

**Illinois Human Services Commission
Workgroup on Rationalizing the Service Delivery System
Sub-Workgroup for Children's Behavioral Health**

REPORT AND RECOMMENDATIONS

on

Improving Service Delivery for Children and Youth with Severe Behavioral Problems

September 2012

SUB-WORKGROUP BACKGROUND

When Governor Pat Quinn extended the Human Services Commission (HSC) in December 2011, he asked the HSC to "address delivery system issues as state agency needs warrant." To this end, the HSC created a workgroup to "rationalize the service delivery system." This workgroup has worked as two separate sub-workgroups — one focusing on the location of maternal and child health (MCH) programs and the other focusing on improving service delivery for children and youth with severe behavioral problems. The latter group has become known as the Children's Behavioral Health Sub-Workgroup, and its recommendations to the HSC are contained in this report.

The Children's Behavioral Health Sub-Workgroup has spent the past several months focusing on the system of services for at-risk children and youth with significant behavioral health problems/challenges.¹ Importantly, the Sub-Workgroup had substantial participation from leaders at key state agencies, who were engaged and very helpful at advancing the Sub-Workgroup's work. These leaders are dedicated to children's well-being and strive to deliver effective services with very limited resources and various systemic constraints. These key state agencies have specific responsibilities, programs, funding, regulatory authority, legislative mandates and regional structures and relationships related to services and supports for children and youth with severe behavioral problems.

There was general agreement among Sub-Workgroup participants that too often children and youth and their families find the current system fragmented, lacking coordination and flexibility, and difficult to access and navigate. The Sub-Workgroup's recommendations for needed improvements are based on full discussions of problems in the current system in Illinois and derived from national public policy and have been adopted by many states and localities. This policy is based on data that support a comprehensive, flexible, coordinated community-based system of services as important to good treatment and good outcomes for children and youth and their families.

SELECTED DATA

¹ The encompassing term for the population of focus is "children and youth with behavioral problems," although different agencies may apply different terms. The Sub-Workgroup agrees that terms "children and youth with behavioral problems" or "children and youth with behavioral health challenges," or "children and youth with mental illness," or "children and youth with serious emotional disturbances," or "children and youth with mental health disorders" all generally describe the same population. If only "children" or "youth" is used, it still broadly refers to "children and youth."

When community-based services are not adequate to maintain children and youth in their home, they can cycle in and out of psychiatric hospitalizations or stay in long-term residential placements, or in a worst case scenario, become involved in the juvenile justice system. Any out of home care, although often necessary, is expensive. Efforts to treat children and youth in their homes and communities can result in significant cost reductions as long as safety can be maintained. A preliminary survey of psychiatric hospitalization and residential costs for state fiscal year 2010² showed:

- \$149 million for acute psychiatric hospitalization paid by the Department Healthcare and Family Services (HFS);
- \$200 million for residential costs for Department of Children and Family Services (DCFS) wards, which are offset by Federal Financial Participation from both Title IV-E and Medicaid;
- \$17.5 million paid by ISBE for the educational costs for students in residential placements who are diagnosed as SED (Serious Emotional Disturbances); and
- \$16 million for children and youth placed residentially through the Individual Care Grant Program, (ICG), which is a financial grant to assist parents/guardians to obtain residential placement or intensive community-based mental health services.

Although these figures are a combination of state and federal funds, significant General Revenue Funds are used for matching the federal funding. Because state agencies keep their cost information differently, comparisons are difficult. More in depth analysis of costs of care across agencies is a priority of the Illinois United for Youth System of Care Expansion Implementation Initiative (IUY). This group is working on gathering data on the numbers of individuals served and their cost per level of care.

There was belief among most of the Sub-Workgroup members that these costs could be lowered if a wider range of community-based services were available. These services include in-home/in-school crisis intervention, short-term community-based residential services, individualized one-on-one services such as coaching and mentoring. These services can be effective and less costly, and do not separate children and youth from the family and community.³

ISSUES IDENTIFIED BY SUB-WORKGROUP PARTICIPANTS

Sub-Workgroup members identified potential problems in the current system (the extent of which should be subject to further investigation and data collection), including:

- Insufficient mechanisms for effective coordination of care between levels of intensity and across service systems for children and youth their families.
- Insufficient coordination within the current treatment continuum that prevents many children and youth from accessing, and providers from being able to deliver the appropriate level of treatment in a timely way.
- Separate, inflexible funding mechanisms for programs and agencies, which effectively fragment services.
- Insufficient supports for families and a lack of family involvement in planning services for their children.
- Due to the lack of access to an array of adequate services, some families are forced to relinquish custody of their children in order for the children to access mental health services.

² State fiscal year 2010 represents July 1, 2009 through June 30, 2010.

³ The Sub-Workgroup recognized that there are some children for whom such community-based interventions are not the best choice, but with expanded community-based interventions, this number should decrease.

- A fragmented administrative structure among state and local entities makes it difficult to conduct strategic planning, oversight, and review.
- Lack of a mechanism for information sharing between multiple systems involved with children and youth and their families.
- Insufficient community-based (school, home and community) services and culturally competent care planning and service delivery for children and youth with severe behavioral problems.
- Too few mental health providers available to treat children and youth with SED.
- Barriers to maximizing the use of all funding resources and taking advantage of blending, braiding, pooling and other integrated funding options to support broad benefit packages in every region of the state.
- Lack of a common database and electronic records for tracking service utilization and cost of services across systems.

It is important to note that not all Sub-Workgroup participants agreed on the degree to which the foregoing items are significant problems. However, the Sub-Workgroup wishes to capture the issues mentioned by participants that need to be subject to further study and analysis.

OPPORTUNE TIME TO MOVE FORWARD

Now is an opportune time to set about building a better system. In 2011, the Illinois legislature passed PA-96-1501, which reformed the Medicaid system. By January 1, 2015, it requires:

1. At least 50% of all Medicaid and All Kids enrollees will be in a coordinated system of care, whereby
2. Reimbursement will be made using pay-for-performance, risk-based capitation methods, thereby creating incentives for
3. Plans to improve health care outcomes, disseminate and utilize evidence-based practices, encourage meaningful use of electronic health record data, and promote innovative service models.

The requirements of Illinois' Medicaid Reform legislation focus heavily on the concept of Care Coordination – a concept that is core to Systems of Care frameworks. This overlap, or synergy, creates an opportunity to increase care coordination across the behavioral health continuum. In light of the 2012 Saving Medicaid Access and Resources Together (SMART) Act, which details 62 fiscal and administrative actions and program changes to manage Medicaid expenditures, and taken in combination with the Affordable Care Act – with its focus on integrated care and outcomes-based treatment models – the Sub-Workgroup believes that a Systems of Care Coordination Model could improve the quality of services, further reduce the utilization of inpatient and residential services, and meet the State's goals and mandates.

During the same period in 2011 and 2012, a group of cross-system agency leaders, advocates, and family members worked on a SAMHSA planning grant for statewide implementation of a system of care for children and youth with behavioral issues - the Illinois United for Youth System of Care Expansion Implementation Initiative (IUY). Since there was significant overlap of the Sub-Workgroup and IUY participants and focus, there was much collaborative work. Many of the IUY goals that build the blueprint to improve and expand services provided by systems of care for children and youth with severe behavioral problems and their families are endorsed by the Sub-Workgroup in this recommendation.

In addition, a statewide task force has been charged with developing a comprehensive five-year behavioral health strategic plan for all ages in Illinois. The actions being recommended by both the Sub-Workgroup and IUY could inform the work of the task force, specifically with regards to children's behavioral health.

RECOMMENDATIONS

1. *ADOPT A “SYSTEM OF CARE” FRAMEWORK*

The Children’s Behavioral Health Sub-Workgroup proposes that Illinois realign the philosophy, service delivery system, organization, and financing of the public children’s behavioral health service system to bring it in line with a Systems of Care framework.

By adopting a Systems of Care framework, Illinois will close system gaps and remove existing system challenges by empowering families and youth to actively engage in their own treatment needs. The Sub-Workgroup’s vision of a Systems of Care philosophy involves a broad array of community-based services and supports for children and youth requiring behavioral health services. Based upon the Child and Adolescent Service System Program (CASSP) model, the Systems of Care framework provides a well-defined set of principles for the development of a behavioral health service system for children and youth (*see Appendix I*). The Systems of Care model suggests that services be organized into a coordinated, community-based networks; build upon meaningful partnerships with families and youth; address individuals’ cultural and linguistic needs; and is family-driven and youth guided. Such a model would ensure that service planning is driven by the needs and preferences of children and their families.

While placements in psychiatric hospitals and residential treatment facilities may still be appropriate for some children and youth, the Sub-Workgroup believes a coordinated community-based network based on the Systems of Care model could, in many cases, significantly reduce the frequency of admissions and expedite discharges, thus decreasing length of stay in psychiatric hospitals and residential treatment placements.⁴

In order for Illinois to successfully adopt a Systems of Care framework – building the partnerships required among families, providers, community members and State agencies, and broadening its array of services – the State will need to plan for, and recognize that, the transition will be an evolutionary process, requiring time for planning, training and capacity building, and a gradual phase-in of fully working systems.

2. *CREATE A SPECIFIC INITIATIVE WITHIN THE ILLINOIS CHILDREN’S MENTAL HEALTH PARTNERSHIP (ICHMP)*

The Sub-Workgroup recommends that the system reform planning effort be delegated and transitioned to the ICMHP as a specific initiative with the necessary changes to their membership and bylaws to support the work.

The ICMHP⁵ mandates align with the reform work being proposed, and the ICHMP’s membership includes many, but not all, of the recommended leaders needed to undertake the reform work.

⁴ Sub-Workgroup members noted that the overall need for residential services may well change with an improved coordinated community-based network based on a system of care concept. For example, improving access to care could bring more children and youth into the system who need residential services, while improving “step-down” services could lead to some children and youth leaving residential care more quickly.

⁵ The ICMHP, which was created statutorily through the Children’s Mental Health Act of 2003, was charged with the development of a five-year Children’s Mental Health Plan with yearly updates and cost savings reported to the Governor. The Act calls for this plan to contain short-term and long-term recommendations to provide comprehensive, coordinated mental health prevention, early intervention, and treatment services for children from birth through age 18. The ICMHP is

The Sub-Workgroup believes that, for an initiative of this magnitude and importance to succeed, there must be an entity to facilitate high-level strategic planning, oversight, review and direction with senior-level representation from state and local entities that are charged with developing and sustaining a system of care for children and youth with severe behavioral problems and related needs.

3. *ROLE OF STATE AGENCIES IN FURTHER WORK*

The Sub-Workgroup believes that it is important to have effective leadership and coordination among state agencies, specifically the Department of Human Services (DHS) – including the divisions of Mental Health (DMH), Developmental Disabilities and Alcoholism, and Substance Abuse – the Department of Healthcare and Family Services (HFS), DCFS, the Department of Juvenile Justice (DJJ), and ISBE.

The Sub-Workgroup further recommends that the Division of Mental Health Child and Adolescent Division be specifically charged with supporting system reform by providing leadership to a multi-system workgroup to continue the system reform planning being done by the Human Service Commission Sub-Workgroup on children’s behavioral health by:

- **Providing recommendations for clinical services and on the standards of care through policy development;**
- **Providing guidelines for how the Child and Adolescent Mental Health System will be monitored for quality assurance consistent with Systems of Care principles and values; and**
- **In collaboration with HFS, convening a workgroup to develop and the process for moving towards a care coordination model for service delivery.**

To carry out these tasks, it is also recommended that the Division receive adequate staffing and resource supports. As part of the multi-system workgroup to be convened by the ICMHP, the Sub-Workgroup supports including representation from families of children and youth with severe behavioral problems who are not affiliated with state agencies.

The state agencies listed above each have specific responsibilities, programs, funding, regulatory authority, legislative mandates and regional structures and relationships related to services and supports for children and youth with severe behavioral problems. The work of these agencies, as well as the work of community-based providers and funders is poorly coordinated, and no entity has a clearly defined leadership role in ensuring a seamless, coordinated system of care.

The Sub-Workgroup believes DMH should play a leading role because it is the state Mental Health Authority for the State of Illinois and is focused primarily on serious emotional disturbances and behavioral health. DMH is most informed about evidence-based practices, treatment models and systems of care for children and youth with severe behavioral problems (although DMH is not the largest funder of services for these children and youth).

4. *IMPROVING CARE COORDINATION*

also required to make recommendations in areas that align closely with the work that the Sub-Workgroup believes is needed.

The Sub-Workgroup recommends development of 1) a plan to research and make recommendations on standards for care coordination designed to integrate and organize services for children and youth and their families across systems, and 2) process for developing a care coordination model children and youth with serious emotional and behavioral problems.

Children and youth with severe behavioral problems often require customized care coordination approaches to meet their complex needs. They may receive treatment through the primary care system, through specialty mental health providers, and/or through other related services such as special education. Additionally, a high proportion of the children and youth with Serious Emotional Disturbances in the Medicaid population are involved with child welfare and/or juvenile justice systems. Coordination of care among these systems, together with engagement and coordination of care with the children's families, would help to improve their care and lead to better outcomes.

Children and youth with severe behavioral problems are also at high risk for co-occurring disorders, such as developmental disabilities and substance abuse, and the intensity and acuity of their needs tend to vary over time. They can benefit from a concerted (not crisis driven) care management focus, which helps to ensure appropriate care, fewer gaps in care, and lower costs as a result of earlier, more preventive and comprehensive approaches. Care coordination should connect children and youth who have complex, multi-system behavioral health care and social needs to providers, facilitate communication among the providers, and track their care and outcomes over time. If successful, care coordination holds the potential for reducing visits to emergency rooms and hospital stays by making sure that children and youth get appropriate, coordinated treatment in the community.

5. STUDY THE ADEQUACY OF THE CURRENT SERVICE CONTINUUM

The Sub-Workgroup recommends an analysis of the current mental health treatment options and their accessibility. Further study is also needed on whether the service continuum, rules or protocols can be strengthened to provide a broad array of services and supports that are reflective of the community strengths, needs, and capacity. This would include the development of a protocol and training for providers and stakeholders to implement early intervention services consistent with current Rule 132.

Services under a system of care model should be provided in the most therapeutic and least restrictive environments, at appropriate intensity, and for the appropriate length of time based on the individual clinical needs of children and youth and their families. Within the Sub-Workgroup, there was some disagreement about the adequacy of home- and community-based services and whether the levels of utilization of psychiatric hospitalization and residential care for this population are appropriate. As part of our work, we must explore whether or not there is an adequate continuum of available and accessible services. If there is not, we should investigate possible systemic barriers there may be to establishing a more robust continuum.

Several members of the Sub-Workgroup also noted that it is essential that there be an appropriate level of care determination across systems to make sure the appropriate level of care is being utilized. It is also important that defined discharge and transition protocols are developed for discharge from hospitals and residential treatment facilities in a timely way and for movement between systems and levels of care. Participants also discussed whether, with the recent changes to the definition of "medical necessity," there is an expanded opportunity to work with children and youth earlier and perhaps without a definitive DSM IV diagnosis. Protocol development and training for providers and stakeholders might enable fuller utilization of Medicaid Rule 132 opportunities for providing services.

Appendix I – System of Care Values and Principles⁶

Definition

A system of care is: A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.

Core Values

Systems of care are:

1. Family driven and youth guided, with the strengths and needs of the child and family determining the types and mix of services and supports provided;
2. Community based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level; and
3. Culturally and linguistically competent, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports.

Guiding Principles

Systems of care are designed to:

1. Ensure availability of and access to a broad, flexible array of effective, evidence-informed, community-based services and supports for children and their families that addresses their physical, emotional, social, and educational needs, including traditional and nontraditional services as well as informal and natural supports;
2. Provide individualized services in accordance with the unique potential and needs of each child and family, guided by a strengths-based, wraparound service planning process and an individualized service plan developed in true partnership with the child and family;
3. Deliver services and supports within the least restrictive, most normative environments that are clinically appropriate;
4. Ensure that families, other caregivers, and youth are full partners in all aspects of the planning and delivery of their own services and in the policies and procedures that govern care for all children and youth in their communities, states, territories, tribes, and Nation;
5. Ensure cross-system collaboration, with linkages between child-serving agencies and programs across administrative and funding boundaries and mechanisms for system-level management, coordination, and integrated care management;
6. Provide care management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that children and their families can move through the system of services in accordance with their changing needs;
7. Provide developmentally appropriate mental health services and supports that promote optimal social and emotional outcomes for young children and their families in their homes and community settings;
8. Provide developmentally appropriate services and supports to facilitate the transition of youth to adulthood and to the adult-service system as needed;

⁶ Excerpted from: Stroul, B. A., & Friedman, R. M. (2011). *Effective strategies for expanding the system of care approach. A report on the study of strategies for expanding systems of care.* Atlanta, GA: ICF Macro. Pg. 2-3.

9. Incorporate or link with mental health promotion, prevention, and early identification and intervention to improve long-term outcomes, including mechanisms to identify problems at an earlier stage and mental health promotion and prevention activities directed at all children and adolescents;
10. Incorporate continuous accountability mechanisms to track, monitor, and manage the achievement of system of care goals; fidelity to the system of care philosophy; and quality, effectiveness, and outcomes at the system level, practice level, and child and family level;
11. Protect the rights of children, youth, and families and promote effective advocacy efforts; and
12. Provide services and supports without regard to race, religion, national origin, gender, gender expression, sexual orientation, physical disability, socioeconomic status, geography, language, immigration status, or other characteristics; services should be sensitive and responsive to these differences.